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IMMEDIATE NEEDS: COURAGE, CAPABILITIES & COMPASSION

THE MAYOR'S CALL TO ACTION ON THE HIV EPIDEMIC

*A Draft Report of the Mayor's HIV Task Force Addressing
the Critical Gaps in HIV Care and Prevention Services.*

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EXECUTIVE SUMMARY

San Francisco has faced a decade of loss with courage, capability, and compassion. Over the last ten years, our city has seen the AIDS epidemic claim thousands of lives, rob us of talent and productivity, and steadily drain our human and economic resources.

Our response has set an example for the nation. Led by seemingly tireless volunteers and far-sighted public and private sector leaders, we have provided education, care, and comfort.

But what we have done -- and can do -- is being outpaced by what needs to be done.

Here is the sad truth: In the next decade, more San Franciscans will live and die with AIDS than in the last. Caseloads and costs are rising. The San Francisco model of AIDS education and care is near collapse.

We Can Choose to Save Lives

We are not helpless. We can choose life over death.

We can reduce the number of new HIV infections, prolong the lives of those infected and provide humane and cost effective care for those who are ill.

We have a humanitarian obligation to make these choices -- and we have a practical obligation as well. The gaps we leave in prevention and care will grow, and as they grow they will consume increasing human and capital resources.

Meeting the challenge of AIDS in the 1990s demands contributions from the greater community. All members of San Francisco's family will need to play a part -- city government, business and religious communities, professionals in every arena, educators, families and friends. We cannot afford spectators.

But even with new commitments from each of us, federal and state government must play a key role. AIDS has struck San Francisco like a disaster, and we require disaster relief in order to cope.

What Needs to be Done

The Mayor's HIV Task Force set out on a "search and define" mission no one had undertaken before. The Task Force, assembled from the City's diverse communities, examined AIDS

related services in three areas: prevention, medical intervention for those who are infected with HIV, and general health care. In each of these areas, our community has made impressive accomplishments. In each area, there are urgent needs requiring our immediate attention.

The AIDS virus continues to spread in our city. Safe sex education and other prevention efforts give us the means to greatly reduce HIV transmission. What prevents us from widespread implementation of those prevention efforts? Inadequate funding and other restrictions.

We must expand education aimed at the general population, but we must make an even greater commitment to groups at most risk. Many in our city -- gay, bisexual, and heterosexual -- continue to have unsafe sexual contracts. Young people, especially those who drop out of school, are homeless, or trade in sex, are particularly at risk for HIV infection. In the years ahead, we will see an increasingly large share of new HIV infections among injection drug users (IDUs).

We can prolong the productive lives of people already infected. Several prophylactic drugs exist which have been proven to slow the progression of HIV and AIDS. Month by month, year by year, new therapies will become available.

But many HIV infected people do not benefit from therapies and care which could prolong their lives. Why? Because they do not know their HIV status, or do not have access to long-term medical care, proper medications or appropriate counseling.

San Francisco's unique network of AIDS-related services has given city residents the ability to live longer, receive comprehensive care, and spend less time in the hospital. Quality outpatient services have kept AIDS-related medical costs down in San Francisco.

But today, local AIDS agencies are facing mounting caseloads and level funding. This cruel paradox -- more need, unchanged resources -- makes it difficult to deliver critical care and support services. Residential care facilities are already operating at capacity. Housing, adult day care and other vital services -- all focused on saving lives and money -- are in short supply.

The Mayor's HIV Task Force has made 53 specific recommendations. Each one is directed at a single goal: enabling the city to fight AIDS more humanely and

effectively. Among these recommendations, our report identifies the urgent need to:

- Step up safe sex education campaigns for the whole community, focusing on communities at greatest risk of new infection, including gay and bisexual men, youth, people in the sex industry, injection drug users and their partners.
- Make drug treatment programs available "on demand."
- Create incentives for treatment programs by easing participation requirements, extending hours of operation, opening treatment centers in locations more accessible to clients, and providing child care in treatment facilities.
- Create a program to evaluate the effect of the provision of sterile injection equipment to injection drug users.
- Give all HIV-infected people access to early intervention services, including appropriate medical and social services and prophylactic drugs.
- Ensure that all HIV infected people have access to a counselor/advisor who can provide or refer them to assistance with financial, medical, or personal concerns.
- Systematically trace unmet needs as identified by counselor/advisors.
- Appoint an HIV Standards of Practice Committee to establish the basic standard of medical care appropriate for HIV infection.
- Provide, through City and private health insurance plans, benefits consistent with services and drugs identified by the HIV Standards of Practice Committee.
- Establish more residential care facilities for HIV-infected people.
- Improve the current health care cost reimbursement system. This is possible only by taking a number of actions:

- insurers should broaden their definition of covered care to include attendant, respite and day care;
- reimbursement rates for sub-acute care must be raised;
- MediCal should revise reimbursement guidelines to reflect the types of health care required by people with AIDS and HIV.

- Establish innovative recruiting programs to hire and train home health aides and increase health, transportation and support services that allow ill people to remain at home.
- Recruit talent and resources from the private sector to help community-based organizations deliver services. Generate supplementary funds, supplies and equipment for these organizations.

We can do these things -- and others. And we can save lives. Again and again, the people of San Francisco have demonstrated that we have the courage and the compassion to do what must be done. We have identified the capabilities in our community. As a leader in AIDS prevention and care, we are rich in the resources of talent, imagination, and creativity. We are not rich in capital resources -- and every day we wait, that situation worsens. With help from our immediate family of communities in San Francisco, and from the State and Federal governments, we can choose short term expenditures for long term benefits, logic over illogic and life over death.

MEMBERS OF THE MAYOR'S HIV TASK FORCE

Don Francis, M.D., D. Sc.
Chair

Frank D. Alvarez
Medical Center Administrator
Chief Executive Officer
Kaiser Permanente Medical Center

Jon Cole
PWA Hotline

Martin Delaney
Co-Executive Director &
President, Board of Directors
Project Inform

Libby Denebeim
President
San Francisco Board of Education

Landy F. Eng
President
C.B.C. International

Kathleen V. Fisher
Managing Partner
Law Office of Morrison &
Foerster

Mary Foley
President
California Nurses Association

Jim Foster
Member
San Francisco Health Commission

Carlton Goodlet, M.D.
Editor & Publisher
Sun Reporter

Shirley Gross
Executive Director
Bayview Hunter's Point
Foundation

Dr. Robert Kirschner,
Rabbi
Temple Emanu-el

Anita Kline, M.S.W.
Social Workers AIDS Network

Congresswoman Nancy Pelosi
Alternate: Steve Morin
Health Assistant

The Most Reverend John Quinn
Archbishop of San Francisco
Alternate: Will Lightborne
General Director
Catholic Charities

Lee C. Smith
President
Levi Strauss International

Rt. Rev. William E. Swing
Episcopal Bishop of California
Alternate: Rev. John W.
Turnbull
Assistant to the Bishop
Episcopal Diocese of California

Paul Volberding, M.D.
Director
AIDS Activities Division and
Chief
Medical Oncology Division
San Francisco General Hospital

Carolyn Wean
Vice President and General
Manager
KPIX

Timothy R. Wolfred
Former Executive Director
San Francisco AIDS Foundation

INTRODUCTION

When future generations of San Francisco residents look back at this time in our City's history and take measure of our courage, capabilities and compassion, two major events are likely to dominate their judgements: our response to the earthquake in 1989 and to the HIV epidemic.

In the case of the earthquake -- a mere 15 seconds in duration -- 13 lives were lost, thousands of families were left without food or shelter and billions of dollars of property was damaged.

In facing this catastrophe, our community came together in an unprecedented way. We did what we had to do to help the City and its residents cope, recover, and face the future with optimism.

We had significant help from others, but it was primarily the inspiring response of our own community that lifted our spirits and lessened the consequences of this terrible disaster.

The HIV epidemic has been with us for almost 10 years. The harm it has caused has been less visible in some ways, but even more devastating. More than 5,000 City residents have died. Countless numbers more of us already grieve the loss of people we knew and loved. The impact of the epidemic on the economic, social and cultural life of the City is also incalculable.

As in the case of the earthquake, San Francisco's response to the HIV epidemic has been extraordinary. We have done more to educate our community, prevent the spread of the virus, and care for infected persons than any other city. In the face of death, we have affirmed life; in the face of pain, we have offered hope.

All these efforts have been provided by caring family members, lovers, colleagues and friends, skilled care providers, visionary community leaders and legions of dedicated volunteers.

We have done so much, and yet we have won only a partial victory. When we look at the future impact of this epidemic, we see problems and challenges far greater than any we have faced thus far.

This community and its people can triumph over the deadly Human Immunodeficiency Virus. But we can do so only

if we fully mobilize the talent, energy and resources of the entire City.

We can further reduce new infections if we want to. We can prolong the healthy lives of those infected if we want to. We can more humanely and economically care for those dying if we want to.

The HIV epidemic requires bold action, not timidity. It requires individuals, groups and institutions to work together in new partnerships, not the promotion of narrow self-interest. It requires risk taking, not caution. It requires the defeat of old fears and prejudices, not their perpetuation.

Today there may still be people in our City who have not lost a family member, lover, friend or acquaintance to AIDS. Within three years that will no longer be the case. The number of people with HIV infections will continue to increase; the number of those who will have died will nearly double.

Soon, the faces of too many new-born babies, young women, fathers and brothers will be added to the gallery of lives cut short by this dread disease. They will be black, white, yellow and brown, rich and poor, and of every religious persuasion. They will be us.

We now face a choice, and the choice is clear. We can fail to act and suffer the consequences of preventable casualties. Or, we can seize the initiative and stem the loss of lives -- for individuals and our community.

This report outlines what our City can do -- with all of us working together -- to prevent the spread of the virus and provide proper care to those who are its carriers. It is a call to action and a statement of immediate needs.

The recommendations are costly, and they will be difficult to implement. They outline what we can and must do to save and prolong life.

AIDS is not just another fatal disease. It is preventable. It is not casually transmitted. It is, at least partially, treatable. It will get worse if it is ignored. It is an epidemic.

Our city's pioneering leadership in combatting the HIV epidemic during the 1980s made San Francisco's initiatives an international model. What we do in the

future here will profoundly influence the health and well being of the entire global community.

We urge you to give this report and its proposals your prompt and most serious consideration. And we hope each reader will accept responsibility to help our City respond effectively and compassionately to the epidemic.

We need the support of everyone in San Francisco to save lives, alleviate suffering and sustain the finest traditions of this caring City.

GUIDING PRINCIPLES

- * We value life. We are concerned with the quality of life of all members of our community.
- * AIDS must receive our urgent and special attention.
- * We must act to take advantage of the opportunities we have to save and prolong life. If we don't, more people will become infected, more people will die. We will all suffer more pain and bear enormous personal and financial costs and weaken the resources of the City. Not to act would be contrary to the community's self interest.
- * Those who battle against any life threatening disease deserve our support and compassion. Acts of discrimination against those who are ill are shameful.
- * We know that homophobia, racism and poverty have each played a role in allowing the HIV epidemic to grow to its present proportions. Discrimination is an enemy of the fight against AIDS.
- * State and Federal Governments have an irreplaceable and essential role to play in guiding and financing the response to this epidemic. As with any large disaster, the Federal government must help communities provide for the urgent needs of their residents.
- * To succeed we must also have more help from all sectors of San Francisco. Business and labor can help, religious and civic organizations can help, political and civic leaders can help, and every individual can help. This may involve offering time, money, talent or understanding.
- * Where existing treatment and prevention models work, they should be supported and expanded; wherever the current system is deficient, new models must be developed.
- * The cost of meeting the challenge of the HIV epidemic will be great, but the cost of failing to do so will be far greater.
- * HIV prevention and treatment programs not only have an impact on the epidemic itself, but also can contribute to the prevention of drug use, drug-related crime, other diseases and social problems, and the organization and delivery of health and human services.

GOALS

- * Our goal is to stop the AIDS epidemic by having everyone completely avoid high-risk sexual and drug-use behaviors.
- * Our goal is to minimize disease for those already infected by making state-of-the-art intervention programs available to all HIV-infected persons.
- * Our goal is to make available quality, efficient and effective care in the least restrictive environment for all people with AIDS in our community.
- * Our goal is to set up a system and identify sources of funding that can serve as a model for other illnesses. This must be done without taking resources from other people in need.

ESSENTIAL SUCCESS FACTORS

- * Community recognition of the unique, grave and extraordinary consequences of the HIV epidemic must be obtained and there must be a commitment of the human and financial resources needed to tackle the HIV emergency.
- * Consensus, coalitions and partnerships must continue to be built among all our city's diverse communities and organizations to maximize success.
- * All levels of government -- local, state and federal -- must continue to work together to plan and finance the delivery of HIV services.
- * Private sector efforts must complement or augment public sector efforts, rather than duplicate them.
- * The multiple HIV-related services must be well coordinated to maximize efficiency.
- * As much as possible, HIV-related services must be integrated into existing services and structures.
- * All delivered services -- educational, health, and support -- must continue to be culturally-, linguistically-, and value-sensitive and be made available in convenient, safe locations.
- * Infectious diseases like AIDS increase their spread as personal stress increases. Programs should

therefore be designed to minimize personal stress in and around infected persons.

* Those requiring services must continue to be included in the planning, implementation and accountability of AIDS-related programs and services.

* There must be continued and expanded evaluation and documentation of the quality, effectiveness and cost of prevention and care programs.

* All those who are or may become ill must receive help without regard to economic status, race, life style or sexual orientation.

SECTION I. PREVENTION OF NEW HIV INFECTIONS

The spread of HIV is not a problem of the past. For each of the next few years, hundreds of city residents will join the tens of thousands of San Franciscans who are already infected with HIV. The consequences -- the impact on family members and friends, the economic loss, the civic, cultural, and social loss, the impact on the health care system -- will be tremendous.

Considering that properly designed and implemented programs which teach people how to prevent HIV infection can eliminate these consequences, such continuing transmission is socially unacceptable and unnecessary.

It is the shared responsibility of government, business, churches, community groups, and schools to teach all San Franciscans how to prevent AIDS. Ultimately, it is the responsibility of each San Franciscan to avoid behavior that is dangerous. The only way to minimize the spread of this virus and the harm it causes is for both the community and its citizens to make this commitment.

Our highest priority now must be those programs targeted to people who engage in high-risk sexual or drug-using behaviors. But at the same time we must continue and improve our general education programs geared toward all children and adults.

Targeted programs must address: those who are already infected (to train them how not to infect others) and those at highest risk of infection (to teach them how to protect themselves).

A. TARGET: SEXUALLY ACTIVE PERSONS

There is clear evidence that the educational programs which have already been undertaken have made an important difference. But there is also clear evidence that more education is needed.

Some people continue to believe that HIV infection poses a threat only for gay men. Others still believe that only intravenous drug users are at risk.

There are many men and women who continue to have unsafe sexual contacts with partners of the same or opposite sex.

Clearly, these individuals still have not integrated HIV protection into their lives. The high rates of sexually transmitted diseases among heterosexual men and women and the documented HIV infections among homosexual men are direct proof that unsafe sexual practices still occur. Low risk communities which do not heed safer sex education now may face escalating rates of HIV infection in the future.

Young people, especially those outside of the education system -- dropouts, homeless youth, street youth, youth in the sex industry, and youth in the criminal justice system -- are particularly at risk for HIV infection. There is evidence that they have a higher incidence of infection because of unsafe sex, multiple partners, and the exchange of sex for money or drugs. Many youths in the "mainstream" also practice behaviors which put them at risk for HIV infection.

The surge in smoking "crack" cocaine and the associated increase in sexually transmitted diseases is an increasing factor in HIV transmission.

Major Problems:

* Insufficient resources have been available to augment existing safer sex programs geared towards gay and bisexual men and young adults. This is true both for whites and members of ethnic and racial minority populations.

* Insufficient resources have been available to augment existing neighborhood prevention programs for youths and adults in areas having high prevalences of HIV infection, sexually transmitted disease and/or drug use. Existing educational messages and delivery systems are not adequately targeted for the diverse groups of people in need of this life-saving information.

* Insufficient resources have been available to expand aggressive, one-on-one counseling services to help high risk individuals prevent infection. These persons include: (1) sexual contacts of injection drug users; (2) persons with sexually transmitted diseases and their partners; (3) youth out of school; (4) individuals trading sex for drugs; and (5) couples that include an HIV-infected person.

* A large number of San Franciscans still do not accept their vulnerability to HIV infection. There is not yet an adequate and comprehensive set of education and

prevention programs that effectively reaches all children and adults in the community.

Recommendations:

1. Expanded, on-going, and pervasive prevention campaigns are needed for homosexual and bisexual men in order to: (a) prevent "slipping" or relapse among those who have adopted safer sex practices; (b) reach groups whom surveys show to be less likely to have adopted safer sex practices; and, (c) reinforce community norms that make safer sex the expected behavior.
2. Neighborhood-based street outreach and community prevention programs need to be augmented in those communities having a high incidence of HIV infection, sexually transmitted diseases and/or prevalence of intravenous drug use. Prevention messages should be developed in consultation with and be targeted to the specific ethnic and racial groups within these high risk communities. Sensitive and trained staff must be available to provide current AIDS and HIV information, safer sex material, condoms and bleach, and referrals to local testing and health facilities and substance abuse treatment programs.
3. The Department of Public Health, either directly or through community-based organizations and private physicians, should hire enough personnel to (1) ensure that all persons with sexually transmitted diseases and their contacts receive counseling sufficient to initiate change and maintain safer sexual behavior, and, (2) expand targeted street outreach to out-of-school youth in all ethnic and racial communities and to youth involved in the sex industry.
4. The Department of Public Health must ensure the availability of ongoing couple counseling services to all couples that include an HIV-infected person and to sexual partners of injection drug users.
5. All HIV-infected persons should be identified through voluntary and confidential or anonymous testing programs and be provided life-long medical, behavioral and psychosocial follow-up and intervention (See Section II).
6. Community, religious, business and other leaders must join with public health workers and take a much more active role in convincing the wider San Francisco community that this virus poses a real threat to everyone and that there are relatively simple ways to avoid that

risk. Stress clearly needs to be placed on women, who, together with their babies, will increasingly share a larger burden of infection and disease.

B. TARGET: INJECTION DRUG USERS

Injection drug users (IDUs) are at grave risk for HIV infection. As the epidemic includes a larger number of injection drug users, their sexual partners and their children, many of the assumptions regarding patterns of prevention and care developed for non-drug using gay and bisexual men may require considerable modification. This is because the IDU population: (a) is 30%-40% female; (b) is frequently of lower socio-economic strata; (c) includes a higher percentage of African-Americans and Latinos; (d) is more often without health insurance and material resources, including access to stable housing; (d) is often drug dependent; and, (e) has different HIV-related clinical symptoms from those of gay and bisexual men.

We have learned a lot about education programs in the process of designing and delivering these programs to gay men. We are also learning more about such programs for IDUs. We must continue to pursue promising models that show success in preventing drug use or treating users.

IDUs are found among members of all races, in every neighborhood, and across all economic and social groups. When talking of IDUs it is more relevant to speak of "us" rather than "them."

There are many factors that can lead to use of addictive drugs. Surely one of the most significant of these is the despair that can result from discrimination and poverty. In addition to drug treatment and HIV education programs, we need broader societal efforts to correct oppressive socioeconomic conditions, especially among people of color.

Major Problems:

* As a community (and as a country) we deliver mixed messages about dangerous substances by seemingly sanctioning the use of some drugs and condemning the use of others. Current drug use prevention programs are hampered by this apparent inconsistency.

* Norm changing drug prevention programs are insufficiently funded to be effective.

* There are an inadequate number of treatment slots available for addicted drug users who want to get off drugs. At some treatment facilities, those who are seeking treatment must wait several weeks to be enrolled in an appropriate program.

* Very few drug treatment slots are available for addicted women, including addicted pregnant women. Because many facilities are not able to accommodate families, addicted women undergoing treatment in residential programs are often separated from their children and families. Almost no services are available for addicted women, including addicted pregnant women.

* There are significant disincentives for using drug treatment programs. These disincentives may discourage drug users from participating in such programs:

- (a) The rules for entering and remaining in these programs are very stringent and frequently discourage all but the very committed from treatment;
- (b) There are too few known ways to treat drug addiction. State-of-the-art behavior change programs, including long-term counseling and support services for drug users and their sexual partners, have not been sufficiently funded;
- (c) While methadone treatment exists for heroin addicts, there are fewer options to treat cocaine addiction;
- (d) Although the effectiveness of treatment programs is directly related to retention time in treatment, there are very few long-term services available.

* Due in part to the lack of personal injection equipment or disinfection solution, injection drug users often share contaminated injection paraphernalia.

* Only a small percentage of injection drug users have been tested for HIV and few programs are available to treat asymptomatic HIV-positive injection drug users.

* The establishment of community-based treatment programs is hampered by the "not-in-my-backyard" syndrome.

* Many IDUs are medically addicted to drugs. They must have their drugs and getting drugs dominates their lives. There is often little value attached to anything else, including HIV prevention.

Recommendations:

1. Fund and support expanded, aggressive, well-designed and long-term drug prevention programs to include culturally and ethnically relevant AIDS education for youth at high-risk for drug involvement. Young people must be taught the risks and dangers of drug involvement before experimentation begins.
2. Promote a city-wide campaign to build consensus around the need for drug prevention and drug treatment programs, including the establishment of neighborhood treatment facilities. Such a campaign must define chemical and substance abuse in a non-judgmental manner. It should present substance abuse as a medical problem involving people with addictive personalities, rather than just a judicial problem involving criminals. A guiding philosophy should be that "acceptance" is key to enlisting, retaining and modifying high risk behaviors.
3. Make available cost-free drug treatment (both methadone maintenance clinics and residential programs) on demand for all injection drug users who desire treatment for their addiction. Once treatment slots are available, implement aggressive outreach programs to recruit drug users into treatment.
4. Expand both in- and out-patient detoxification and 12-Step programs.
5. Require less stringent rules for entering and remaining in treatment programs.
6. Utilize a variety of strategies to encourage the ongoing use of drug treatment and prevention programs, including the availability of long-term treatment services, operation of programs for extended hours, the use of mobile treatment vans and 24-hour satellite clinics in medical facilities and the expansion of community storefront facilities.
7. Expand drug treatment programs for women and locate these programs where they are more easily accessible to women. Expand programs which allow women with children to undergo treatment without being separated from their families.

8. Ensure that family planning, prenatal care and safer sex education programs are included as part of all drug treatment programs.

9. Design, implement and evaluate sustained programs for treatment of stimulant addiction, including new and effective ways to treat injection cocaine users. Encourage research examining these alternatives in San Francisco.

10. Train all injection drug users, through drug treatment facilities and street outreach programs, how to clean injection equipment and the importance of adherence to this practice. Such training programs should encourage HIV testing of injection drug users and their entry into early intervention and drug rehabilitation programs.

11. Expand programs to ensure that health workers maintain contact with all out-of-treatment injection drug users to provide information, support and access to treatment programs.

12. As part of a comprehensive program to reduce HIV transmission, establish a pilot program to provide injection drug users with sterile injection equipment. The program should be carefully monitored and evaluated with special attention given to any adverse effects such as increasing drug use among participants (see Appendix 1).

13. Expand routine, voluntary HIV testing programs into all locations where addicts seek treatment and as part of street outreach programs.

14. Establish early intervention programs for HIV-positive injection drug users and their sexual contacts in close proximity to drug treatment centers and in high prevalence communities (Section II).

15. Public housing and private residential facilities should designate specific slots for families in recovery. Public housing community centers should be targeted as sites for education, prevention, treatment and rehabilitation services for the prevention of substance abuse and the spread of HIV infection.

16. Make available supportive foster and adoptive care for infants born to HIV infected mothers. Explore ways to reimburse grandparent and intrafamily care.

17. Develop and evaluate new and innovative drug treatment and prevention programs to minimize the risk of

HIV infection and maximize the chance of drug avoidance. County and private mental health agencies and academic researchers must be challenged to develop and evaluate community based state-of-the-art behavior modification programs.

SECTION II. EARLY INTERVENTION

In addition to all of the efforts we must take to prevent new infections, we must be equally concerned about slowing disease progression in those already infected. Evidence suggests that preventive treatment will prolong productive life, decrease hospitalization episodes, and may decrease overall medical costs. It is essential that all HIV-infected persons have access to ongoing prevention and treatment programs.

Recently, two major interventions have been approved for widespread application, AZT (zidovudine) and aerosol pentamidine. These medications have prophylactic value when given before or after the onset of clinical disease. With time, other treatments will be discovered that can be used as effective interventions.

Major Problems:

- * Not all HIV-infected persons know they have been exposed and/or are unaware of their antibody status.
- * Not all HIV-infected persons understand the importance of early medical intervention and many fear the stigma and discrimination that may result from a positive test result.
- * Not all HIV-infected persons receive medical follow-up and/or treatment.
- * Not all HIV-infected persons who do receive medical follow-up receive preventive (behavior and psychosocial) counseling.
- * Not all HIV-infected persons have access to counselors who can advise them about the legal, medical, financial and health insurance issues involved in their HIV status.
- * There is inadequate monitoring of the unmet needs of HIV-infected persons.
- * Because of low reimbursement rates from a variety of sources, physicians are often unwilling to provide HIV-related care.

Recommendations:

1. Expand current educational campaigns to encourage all potentially at-risk persons to be voluntarily tested.
2. Establish routine voluntary anonymous and/or confidential testing programs in all sites where at-risk persons seek medical care.
3. Remove all disincentives to being tested. Ensure that high quality and convenient testing facilities able to provide test results rapidly are available to all. Specifically, it is vital that testing be performed with appropriate pre- and post-test counselling, in accordance with strict laboratory standards and with the protection of confidentiality. Provide accurate benefits and legal counseling to persons being tested.
4. The City should continue to ensure that HIV-positive individuals are not the subject of illegal discrimination. Additionally, public officials, the business community and civic and religious leaders should help stamp out other forms of harmful discrimination.
5. All persons who test HIV positive must have access to long-term care, known as early intervention. Such managed care, provided by professionals knowledgeable about the latest medical and public health aspects of HIV and sensitive to the language, culture and values of the patient, should include: regular physical examinations, laboratory studies, behavioral counselling, psychosocial support, administration of medications and treatments and information and referrals appropriate to the needs of the individual. Such care should include access to prescription drugs for the treatment of HIV infections or for the treatment and/or prevention of opportunistic infections or malignancies.
6. The City should designate an HIV Standards of Practice Committee to establish the basic standard of medical care appropriate for HIV infection. These recommendations should be issued initially by the HIV Standards of Practice Committee no later than April 1, 1990, and updated and published regularly to reflect the latest medical developments.
7. No person should be denied the early intervention services discussed above. Such services should be provided by private insurers where possible. These services should be made a covered benefit under the City's

employee health programs. In addition, the City should, by example and otherwise, actively encourage other public and private employers in San Francisco to provide similar health benefits to their employees. Those without these benefits should receive these services through publicly funded programs.

8. Funding for early intervention services should not be provided at the expense of existing medical and public health programs, and will therefore require additional resources at the local, state and federal levels.

9. San Francisco should actively advocate for adequate financial incentives be available for providers supplying early intervention services.

10. Although it is not necessarily the public sector's responsibility to provide all early intervention care, it is the public sector's responsibility to ensure that each and every HIV-infected person has access to such care. To ensure the delivery of proper care and services, each infected individual should have access to a specifically identified person who will serve as that individual's counselor and adviser. As part of the health care team, these counselor/advisors should assist infected persons in obtaining the various services required and to advise them regarding the medical, legal, and financial implications of HIV infection. In addition, they should counsel the HIV-infected person and their at-risk contacts on how to prevent infection.

11. Establish an ongoing system to assess unmet needs of HIV-infected persons. All case managers and counselor/advisors must be joined together with a city-wide reporting system that will regularly track unmet needs.

SECTION III. CONTINUUM OF CARE

The San Francisco model is collapsing and is in desperate need of additional resources.

Because of both medical advances in AIDS care and San Francisco's array of services, San Francisco's HIV-infected patients live longer and have cut down the time they spend in hospitals. From 1983 to 1987 median survival time for San Franciscans with AIDS rose from 11.1 to 15.6 months, a 41% increase. Decreased hospital usage is both beneficial for ill persons and helps keep costs down, but hospital stays still claim considerable resources. San Francisco has the hospital-bed capacity to care for AIDS patients requiring acute hospital care.

The basis of care for HIV disease is a network of comprehensive services available to all infected persons throughout the course of their infection. Medically appropriate care and psychosocial support should be available in convenient and safe environments that are sensitive to differing cultural backgrounds and sexual orientations.

Ideally, these services are delivered in outpatient settings whenever possible in order to minimize expensive acute hospital services. For this to be successful, extensive networks of support services are essential.

The heroic contributions of San Francisco's community-based organizations have been unmatched in any other major city. Relying heavily on volunteer labor, these organizations have done an outstanding job of providing community services for individuals with HIV infection. They often provide services not otherwise available through the health care delivery system. Their efforts are the major building block of what has been praised throughout the world as "the San Francisco model." But the financial resources to provide for out-of-hospital care have fallen woefully far behind the increasing number of ill persons. In addition, the relative number of volunteers has declined.

An additional stress to the care system will arise in the future. As the number of people with AIDS rises, and as new drugs boost their life expectancy, AIDS dementia will increasingly challenge the system. People with even moderate dementia often require special services, including 24-hour supervision. This is a critical issue, given the exhaustion already evident among health care professionals, para-professionals, support staff, families, loved ones and volunteers.

Major Problems:

- * AIDS-patients often must remain in the hospital when it is no longer medically indicated because there is no other place available to care for them.
- * The lack of adequate housing is the single greatest non-medical gap in care. This problem has an enormous impact on the home delivery of all treatments, whether medicinal, nutritional, or supportive, all of which assume access to a clean kitchen, a bathroom and a bed in a heated and safe setting. Lack of housing can significantly affect the general health status of patients.
- * Residential-care facilities are already at capacity with waiting lists and the demand for home-care services is running ahead of projections.
- * Some health insurers still do not pay for cost-saving out-of-hospital care.
- * Because low reimbursement rates discourage the private sector from building and/or maintaining sub-acute care facilities, there is a great under-supply of such facilities.
- * Many community-based organizations are faced with increasing caseloads and relative decreases in financial resources and volunteers. They will need additional support to provide appropriate assistance to the changing population of HIV infected persons.
- * HIV patients, because of their rapidly fluctuating medical conditions, do not always fit into the available modes of medical and housing services that are structured for people with more stable conditions.
- * There are inadequate facilities to care for HIV dementia patients.
- * There are inadequate adult day-care facilities and insufficient transport to move patients from home to these facilities.
- * There are inadequate facilities convenient and sensitive to youth available to treat HIV-infected and ill youth who are on the streets. There are inadequate facilities for drug treatment programs, for long-term housing, and for hospital-based services for homeless and street youth. Neither are there adequate services for gay adolescents who are likely to engage in high-risk behavior.

* The eligibility requirements to pay for services to people with HIV disease are sometimes still based on the restrictive federal epidemiologic definition of AIDS rather than on actual physical condition.

* There are inadequate support services available to friends, families and health care professionals who care for people with HIV disease.

* Current facility licensing regulations can act as a disincentive to private and non-profit organizations which want to establish basic residential facilities with custodial care.

* The cost of acute hospital care will increase in proportion to the increases in caseloads. Adjusting budgets, especially fixed public budgets, for these increases can cause considerable budgeting problems.

Recommendations:

ACUTE CARE

1. Hospitals, third party payers and public payers must adjust their budgets to accommodate the expected increase in patients.

RESIDENTIAL AND HOME CARE

1. Establish more places to house HIV-infected persons.

2. Establish more residential-care facilities for ill HIV-infected persons.

3. Encourage health care insurers to broaden their definition of covered health care costs to include attendant, respite, and day care.

4. Urge Medi-Cal to: 1) increase reimbursement levels for home care; 2) provide for up to twenty-four hours of services when needed and, 3) allow flex time or split-shift time to be utilized instead of the current consecutive hours now mandated.

5. Substantially increase home health and support services, including attendant care and home maker services, to maintain ill people at home.

6. Establish innovative recruitment programs to hire and train home health aides.
7. Substantially increase day care services, including transportation programs, for those people who are alone during the day while their primary care provider is away.
8. Encourage employers to allow care-giving employees to utilize flex time or split-shift time.
9. Increase respite services to relieve the burden on families, loved ones and caregivers who attend to patient needs.

SUB-ACUTE CARE

1. Provide additional sub-acute care beds, which were in short supply even before the AIDS epidemic. The supply of sub-acute care facilities must be increased by raising government reimbursement rates to cover the realistic costs of sub-acute care.
2. Establish a multi-tiered, primarily sub-acute facility which will allow people who need residential care or day care to utilize one location with services varied to match their episodic relapses and recoveries. This model, breaking from the tradition of separate institutions, each with a single level of service, would provide services ranging from intensive nursing to residence halls with group meals.
3. Support a new state license category for residential facilities offering custodial care with a minimal medical staff. As license standards are sorted out, encourage Medi-Cal to support this alternative approach to care that is both cost-effective and humane.
4. To provide care for those with dementia, a small number of secured nursing beds must be provided.

INCREASING VOLUNTEER SERVICES

1. Develop and implement a large-scale centralized volunteer recruitment program to tap into corporate, religious, service club and other volunteer programs.
2. Give ongoing support and training to community-based organizations to build administration and management

systems to maximize the retention of volunteers and prevent the emotional "burn out" that often accompanies front line responses to the epidemic. This should be done by calling upon the talent and resources of the private sector.

3. Generate supplementary funds, supplies and equipment for the infra-structure of community based organizations that will continue to render critical services to HIV infected persons, their families and loved ones.

YOUTH

1. Expand facilities sensitive to the needs of youth on the streets to treat the medical and psychosocial problems associated with HIV and other sexually transmitted diseases. These services should be delivered to youth in convenient neighborhood locations.

2. Deliver appropriate and accessible medical, psychiatric and support services that are confidential and affordable (or free of charge) to youth in need.

APPENDIX 1

Policy Recommendations of the Mayor's HIV Task Force on Clean Needle Exchange

1989

Several areas of the world have provided sterile injection equipment to drug addicted persons. The conclusions to date from the experience at these sites have been:

1. They do not increase drug use.
2. They increase referrals to drug treatment programs.
3. They may reduce HIV transmission.

General Premis: Needle exchange may well be an important public health measure to control HIV infection among Intravenous Drug Users (IVDUs). We are concerned, however, that such a program might incorrectly be perceived to be a complete solution, which it is not. We believe it is most likely to be effective only when part of a comprehensive approach which includes:

1. Priority on treatment for opiate and stimulant users;
2. Outreach for hard-to-reach addicts to include;
 - Referral for treatment
 - Training on safe injection (bleach)
 - Training on safe sex
3. Provision and evaluation of sterile injection equipment;
4. Voluntary (confidential and anonymous) HIV testing, counseling, and medical follow-up for infected persons and their sexual partners;
5. Confidential counseling, testing, and appropriate treatment programs in jails and prisons;
6. Social services to support families of HIV-infected drug users, and;
7. Evaluation of all components.

APPENDIX 2

TEXT OF RESOLUTION
BY THE MAYOR'S TASK FORCE ON THE HIV EPIDEMIC
APRIL, 1989

Re: Adverse Public Health Impact of Immigration and Naturalization Service Action

The recent jailing of Hans Paul Verhoef, a health educator from the Netherlands bound for a health conference in San Francisco, is cause for great public health concern.

Mr. Verhoef was jailed by the Immigration and Naturalization Service (INS) in Minnesota because he admitted at entry to the United States that he had AIDS. The INS was following U.S. law which in 1987 added AIDS to the list of seven diseases which can be used as grounds to prevent entry into the United States.

The purpose of this law is presumably to protect the public's health. It unfortunately does the opposite for the following reasons:

1. It gives the confusing message to the public that HIV can be transmitted by casual or air-born routes like internationally quarantinable diseases.

2. It is contrary to the World Health Organization's policy of open and free travel for HIV-infected persons (which the United States Public Health Service supports).

3. It adds disincentives to the United States policy encouraging voluntary HIV testing by demonstrating that we will jail infected immigrants from elsewhere.

4. It undermines the trust necessary to communicate risk reduction messages from government public health agencies to at-risk persons.

5. It impedes communication and learning between international AIDS experts since some of these are HIV-infected.

6. It will adversely affect the June 1990 International AIDS Conference in San Francisco since many HIV-infected persons from abroad will want to attend and should be welcomed.

We condemn the procedures followed by the INS. They fly in the face of much of what we have been trying to accomplish in the battle against AIDS.

We therefore recommend that you:

1. Urge that the law be repealed to reflect internationally accepted principles for HIV infection.
2. Until the law is repealed, urge that the INS establish interim guidelines to grant "humanitarian waivers" to all HIV-infected travelers.
3. Communicate these recommendations to national political and public health leaders.
4. Call on President Bush to issue an apology to Mr. Verhoef.

APPENDIX 3

FINANCIAL ESTIMATES: NEEDS AND GAPS

SAN FRANCISCO - 1990

(\$ MILLIONS)

CATEGORY	EXISTING RESOURCES	PROJECTED NEED	ESTIMATED GAP
I. Prevention			
A. Sexually Active Persons	12	25	13
B. Injection Drug Users	13	31	18
II. Early Intervention	10-25	103	78-93
III. Continuum of Care	123	151	28
	158-173	310	137-152

FINANCIAL ESTIMATES

SAN FRANCISCO - 1990

(\$ MILLIONS)

<u>I.</u> <u>PREVENTION</u>	<u>PROJECTED NEED</u>
A. Sexually Active Persons	
One-on-one Counselling	7.495
Targeted Group Outreach	1.425
Community-Wide Interventions	1.890
Paraphernalia Exchange	.360
Training	.330
Media	1.700
	<hr/>
Sub-Total	13.200
Current Expenditures	12.130
	<hr/>
Total	25.330

FINANCIAL ESTIMATES

SAN FRANCISCO - 1990

(\$ MILLIONS)

I.	<u>PREVENTION (CONT'D)</u>	<u>PROJECTED NEED</u>
B.	Injection Drug Users	
	Residential	14.520
	Outpatient	.780
	Methadone	2.570
	Outreach	.470
	Sub-Total	18.340
	Current Expenditures	12.950
	Total	31.290

FINANCIAL ESTIMATES

SAN FRANCISCO - 1990

(\$ MILLIONS)

<u>II. EARLY INTERVENTION*</u>	<u>PROJECTED NEED</u>
Visits	18.564
Drugs	70.668
Laboratory	13.702
Total	102.934

* It is difficult to develop solid estimates of current expenditures on early intervention services. Therefore we have calculated total needs and assumed existing expenditures are included in these calculations.

FINANCIAL ESTIMATES

SAN FRANCISCO - 1990

(\$ MILLIONS)

III. <u>CONTINUUM OF CARE</u>	<u>PROJECTED NEED</u>
Outpatient Care	7.052
Inpatient Care	16.316
Extended Care	1.599
Residential Care	1.285
Support Services	2.277
Sub-Total	28.529
Existing Expenditures	122.751
Total	151.280

LETTER OF TRANSMITTAL

To the Honorable Art Agnos, Mayor, and to the People of San Francisco:

In January, 1989, Mayor Agnos appointed a blue-ribbon citizens committee to formulate a plan that would indicate what we could do as a community to combat the spread of HIV and provide proper care for persons with AIDS.

The Task Force of 20 members was selected to represent a broad cross-section of the community. It includes leaders from government, business, and religious and community organizations. Some of the Task Force members took on this assignment as experts in the field; others had been involved in a more modest way in education, treatment or counseling roles; a few had only general knowledge of the epidemic and its impact on the community. Two people on the Task Force are HIV positive, and one of them has developed AIDS.

During the past 12 months, the Task Force has set out to fulfill its charge. It has taken every possible initiative to educate itself, examine alternative ideas and arrive at a broad consensus about the actions it should recommend. It has met as a group and in sub-committees. It has consulted with local and national leaders in the battle against the HIV epidemic. It has met with care providers and persons with AIDS. It has reviewed efforts underway and planned in other communities. The Task Force has done this with all deliberate speed. Task Force members are painfully aware that we can ill-afford any further delay in implementing the urgent policy proposals that follow.

As this report is being released, the San Francisco model is severely threatened by demands that have overwhelmed its resources. Unless this report is acted on by all of us the San Francisco model will collapse.

The HIV epidemic is the single most serious threat our City can anticipate as we begin the decade of the 1990s. It will affect all of us one way or another. It is imperative that we all join together in common purpose to save lives, help those who become ill and preserve the vitality and character of our City. Our report outlines in principle what needs to be done. The details of how this will be accomplished will be further elaborated in formal and informal communications

with public, private and community leaders, organizations and institutions in the months ahead.

The submission of this report does not mark the conclusion of our work. Rather, it signifies the start of a new phase of our efforts. We plan to discuss our findings with people throughout the community. We must enlist their support for what needs to be done. We want to work with them and others to help implement these critical initiatives that are so vital to the public, spiritual and economic health of our community.

It has been an honor and a privilege for me to chair the Task Force. Our distinguished members have been hard working, thoughtful and cooperative as they have executed this important assignment. They have done their work and done it well. Special thanks are also due to the Mayor's Office, the AIDS Office at the City Department of Public Health and to other City agencies. Financial and other support has been provided by Kaiser Foundation Hospital, Levi Strauss and Co., and Morrison & Foerster.

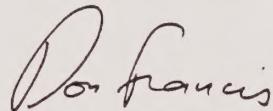
Don Francis, M.D. D.Sc.

Don Francis

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